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AUTHOR Bakke, Bruce L.
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ABSTRACT

This guide to preventing self-injurious behavior, in question-and-answer format, is intended for parents, teachers, and other caregivers of people with disabilities. It describes the more common types of self-injurious behavior, discusses methods for identifying causes of self injury, and outlines interventions. Specifically, the guide covers: (1) characteristics of self injury, including a definition, incidence data, and particular disabilities often associated with self injury (i.e., autism, Cornelia de Lange syndrome, Fragile X syndrome); (2) causes of self injury, focusing on current beliefs that self-injurious behavior usually has multiple causes, the role of medical problems, the possible role of dietary factors, self injury as a form of communication, and the relationship of self stimulation to self injury; and (3) treatments for self-injury, such as drug treatment, communication training, providing a positive environment with more rewarding activities than self injury, and response suppression procedures. Eleven additional sources of more information are listed. (DB)

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SELF-INJURY

Answers to Questions for Parents, Teachers, & Caregivers

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The University of Minnesota's Institute for Disabilities Studies, directed by Travis Thompson, Ph.D., was established in 1987 to conduct basic and applied scientific research on preventing and intervening in developmental disabilities, and to design treatment and educational methods for people with disabilities. The Institute's research focuses on the prevention of disabilities arising from poverty; on behavioral and emotional problems associated with disabilities; and on disabilities that occur later in life. Because no single field of study can solve the complex problems of developmental disabilities, the Institute for Disabilities Studies is dedicated to interdisciplinary collaboration, making it a unique program within the University of Minnesota and across the country.

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University of Minnesota

Written by Bruce L. Bakke, Ph.D.,
Institute for Disabilities Studies,
University of Minnesota.
Designed by Anna Fellegy;
cover by Geri Thompson.

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The following contents do not necessarily represent the positions and policies of each organization mentioned in this brochure.

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One in five people with mental retardation injures her or himself, causing pain and suffering to themselves, their families and others around them. This guide for parents, teachers and other caregivers of people who have developmental disabilities describes the more common types of self-injury and discusses methods for identifying causes. Interventions are discussed and information is provided concerning sources for further assistance.

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CHARACTERISTICS OF SELF-INJURY

What is self-injurious behavior and how common is it?

Self-injurious behavior (SIB) is repetitive behavior that causes physical harm. Usually the behavior takes a very similar form every time it occurs -- for example, one child may bruise the side of her head by hitting herself with the knuckles of one hand. Another may repeatedly bite one place on his right wrist. SIB is different from suicidal behavior and suicidal gestures, and is seen almost exclusively in people with mental retardation and other developmental disabilities. In most instances, self-injury can be successfully treated, especially by intervening early in the development of the problem. While self-injury is rarely life-threatening, without treatment it can sometimes worsen to the point of causing permanent damage. A few people with severe self-injury blind themselves or suffer hearing loss, destroy parts of their bodies (e.g., portions of fingers or lips), produce concussions, or cause repeated damage which leads to lingering infections.

Do all children who bump their heads or hit themselves develop the problem of self-injury?

No. About 17% of infants without a disability periodically hit their heads against their cribs or occasionally hit their head or face with their hand when they are tired or frustrated. Nearly all non-disabled infants stop hurting themselves by the time they are two years old. But as many as one in five children with mental retardation continue hurting themselves periodically for months and years, sometimes severely.

My four year old son slaps his face repeatedly, but he doesn't leave any bruises, just reddened skin. Is this a problem?

Face slapping or any other behavior that is performed often enough or intensely enough to cause reddening or breaking of the skin, bruises, bleeding, or other signs of tissue damage should be discussed with a professional experienced with self-injurious behavior in people with developmental disabilities. Sources of help include special education teachers, pediatricians, behavior analysts, social workers, child psychiatrists and psychologists, and pediatric neurologists.

Do children with some particular disabilities have more problems with self-injury than children with other disabilities?

Children with several uncommon disabling conditions, such as Autism, Cornelia de Lange syndrome, Fragile X syndrome, Lesch-Nyhan syndrome, and Rett syndrome have problems with self-injury more often than children with other developmental disabilities. However, since as many as 20% of children with disabilities display self-injury at some time in their lives, the problem extends well beyond these rarer disabilities. People wishing further information about specific disabilities often associated with self-injury should contact the resources listed at the end of this brochure.

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CAUSES OF SELF-INJURY

What is known about the causes of the problem?

Thirty years ago, some writers speculated that children who hurt themselves were born the same as other children but that their self-injury resulted from a cold or detached style of mothering. There is no evidence to support this theory.

Today, most experts realize that self-injury usually has more than one cause. There may often be an underlying biological tendency for a child to self-injure. How often, under what circumstances and how intensely the child self-injures often depends on learning experiences, which can cause the self-injury to decrease or sometimes grow much worse.

Can medical problems cause self-injurious behavior?

Several medical conditions can lead to self-injury. Children with ear infections, for example, may try to reduce their discomfort by hitting or slapping at their ears. Similarly, they may repeatedly scratch at an area of itching skin, and continue to scratch when the skin begins to heal. Once the earache or skin irritation clears up, the self-injury usually stops. If the self-injury continues after the medical problem is over, another cause for the behavior should be considered.

Can dietary factors such as sugar, artificial coloring, or other food additives cause self-injury?

There is little carefully done research on the effects of diet or food ingredients on self-injury, or on megavitamin therapy as a treatment for self-injury. The studies on food and hyperactivity (extreme restlessness and overactivity) in children show no consistent effect of diet on behavior. For most children, activity level does not appear to be changed by the items in a normal diet, but a small number of children may be affected by diet.

I often see my child hurting himself when he is angry. For example, he bumps his head when it is time to put on his shoes. Why does he do this?

Children sometimes learn to avoid or delay doing things that they don't like by hurting themselves. Perhaps the youngster finds it difficult to put on his shoes, or does not enjoy the activity that will follow once he is dressed. Maybe he just prefers to continue with whatever he is doing. Because it is

difficult for adults to continue to request something from a child who is engaged in self-injury, some children learn to control what happens in their lives by hurting themselves. Self-injury is especially likely to be learned if the child cannot speak and has no other effective way to communicate.

My child speaks only a few words. Is it possible that she is trying to tell us something by hurting herself?

Self-injury can be an effective method for getting attention from adults, because the parent's natural response is to immediately go to the child to see what is wrong and to try to stop the self-injury. Sometimes it is necessary for adults to physically prevent the child from injuring him or herself. Children who have difficulty communicating can learn that attention can be gotten at any time by hurting themselves. Beyond simply gaining attention, children can also learn to hurt themselves to obtain other things they need or want. These may include preferred foods, favored activities, or being left alone. Self-injury is disturbing and even alarming to adults, and they will do whatever they can to stop it. Adults often offer various things to the child until s/he stops self-injuring. Unfortunately, the child may self-injure for a different reason the next time, and the process of adult guessing will be repeated again and again, unless a more satisfactory form of communication is developed.

Even though our child communicates very well, he threatens to scratch his face or hurts himself in other ways when he wants something he shouldn't have. Since he tells us exactly what he wants, communication can't be the reason for his self-injury.

Self-injury can still be a powerful and quick way for a child to get what he wants, at least part of the time. Seeing children deliberately hurt themselves is extremely upsetting for parents and others. It is very difficult not to give in at least occasionally, and provide what the child wants to stop the self-injury. Although it is not intended, this rewards the child's self-injury and can cause the self-injury to continue.

So far, none of this seems to fit my child. She has Down syndrome, and had a complete medical evaluation showing no medical problems that could account for her self-injury. It doesn't seem to be an attempt to communicate or to get attention. In fact, she likes to be alone. She rocks for long periods of time. When she rocks, she bumps against the wall and has caused a bruised spot that seems never to heal.

Some children perform a repetitive movement that results in skin, muscle, or even bone damage because it is repeated over and over again. The stimulation produced by the repeated movement may be pleasant to her, much as rocking is enjoyed by a baby. The injury is a by-product of the way the movement is performed (in this case, by constantly bumping against the wall). Similar problems are seen in children who have impaired vision. A child with a visual handicap might learn to press a finger into the eye because of the flashes of light this mechanical stimulation produces through the optic nerve. Obviously, this can cause physical damage to the eye.

I can see that repeating the same movement can cause injury as an accidental by-product of the movement. However, when my son bangs his head, it seems that his only purpose is to damage himself.

A different kind of self-stimulation can result from self-injury: Sufficient pain causes the release of "endogenous opioids," which are natural chemicals in our bodies that protect us from feeling intense pain. Endogenous opioids can also produce feelings of euphoria, such as the so-called "runner's high" that some people experience when running marathons. Some people may self-injure in order to be stimulated by these pleasant effects of endogenous opioids. Research on endogenous opioids as a cause of self-injurious behavior is just beginning, and may lead to new treatments for some self-injury.

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TREATMENTS FOR SELF-INJURY

With so many different causes, how is self-injury treated?

The first step is to try to discover the causes of the child's self-injurious behavior. It is important to identify any medical problems that might be responsible. This requires a thorough examination by a physician familiar with children with mental retardation. Other causes for self-injury can be identified by examining the circumstances in which the child self-injures. When the behavior occurs primarily in adult company but rarely when the child is alone, it is often directed at getting attention or other things that the child needs or wants. Self-injury that occurs when the child is asked to do something or during activities the child dislikes may be attempts to avoid unpleasant activities. The child who is just as likely to self-injure when alone as when he or she is with adults may be showing behavior that is a form of self-stimulation. Each of these causes suggests a different avenue of treatment to a professional experienced in treating self-injury.

Once causes are identified, what treatments are available?

A range of treatments are available, including providing more rewarding activities at which the youngster can easily succeed, providing communication training, decreasing the demands made on a child, and drug treatment. A positive environment with appropriate training, social, recreational, and other experiences must provide the foundation for any treatment for self-injury. That environment must provide activities with the correct amount of challenge: Tasks should be easy enough for the child to be successful. Assessing the environment of a self-injurious child, and selection and use of effective treatments, usually require the assistance of a developmental disabilities professional. Treatments should be matched to the cause identified. For example, children who learn to hurt themselves to gain attention from parents, teachers or other people caring for them can usually be

taught to seek that attention in healthier ways, making it unnecessary for them to hurt themselves. Teaching children to develop other communication methods, or to use other constructive ways of gaining adult attention is often enough to reduce self-injury. In other circumstances, self-injury is thought to be caused mainly by a biological condition, such as a brain chemical imbalance. In such instances, it may be necessary to treat the underlying problems with a drug intended to correct the imbalance.

My child takes medication for self-injury. She still hurts herself, but not as often.

Medications are currently one of the most common forms of treatment for self-injury. The medications usually tried for self-injury are called neuroleptics, which are the same types of drugs used for treating some major mental illnesses. These and other drugs can be helpful for certain conditions, however they are rarely used alone except when the person clearly has mental illness as well as mental retardation. A disadvantage of some drug treatments is that they can have both immediate and long-term unwanted side effects, some of which can be very serious. Treatment with medication always requires consultation with a physician.

Some friends have suggested that I spank my daughter for self-injury. Is this a good idea?

No. Positive, non-aversive interventions are usually sufficient to reduce or eliminate self-injurious behavior, and parents are urged not to use spanking, slapping, or scolding to control self-injury. Punishment procedures by themselves are not an appropriate treatment. However, as one part of a carefully designed overall treatment program in closely supervised clinical settings, various response suppression procedures have been reported to be effective under some circumstances. Such procedures are controversial. Parents wishing further information on this topic are encouraged to contact the following resources:

1) The position statement on the use of aversive and deprivation procedures of the Association for Retarded Citizens Minnesota (ARC MN). This statement is available by calling ARC MN at (800) 582-5256 or (612) 827-5641, or from the Institute for Disabilities Studies, (612) 627-4537. Addresses for both organizations are listed among the resources at the end of this brochure.

2) The 1989 National Institutes of Health Consensus Development Conference Statement, *Treatment of Destructive Behaviors in Persons with Developmental Disabilities*. Single copies can be obtained from the Director of Communications, Office of Medical Applications of Research, National Institutes of Health, Building 1, Room 260, Bethesda, MD 20892.

When my child is busy, there seems to be less self-injury.

Whether at home or at school, keeping a child occupied with enjoyable activities at which they can easily succeed, and providing frequent adult attention will often reduce self-injury. The key to reducing self-injury by providing these activities is to promote the child's active responding and learning of new skills. It appears that it is most helpful to have the child participate in doing things, rather than doing things to or for the child.

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FOR MORE INFORMATION ABOUT SELF-INJURY

This brochure was produced by the Institute for Disabilities Studies, a program of the University of Minnesota, and was written by Bruce L. Bakke, Ph.D. Support was provided by The Minneapolis Foundation. This material provides an introduction to the problem of self-injurious behavior in people with developmental disabilities. Further information can be obtained by contacting the Institute or the people and organizations listed below:

Institute for Disabilities Studies
~~Technical Assistance Program~~
University of Minnesota
2331 ~~2221~~ University Avenue Southeast, Suite ~~145~~ 152
Minneapolis, MN 55414
(612) 627-~~4537~~, or FAX (612) 627-4522
4500

Association for Retarded Citizens Minnesota (ARC MN)
3225 Lyndale Avenue South
Minneapolis, MN 55408
(612) 827-5641, or toll free (800) 582-5256

Nonaversive Behavior Management Information & Referral Service
National Research & Training Center on Community-Referenced, Nonaversive Behavior Management for Students with Severe Disabilities
San Francisco State University
San Francisco, CA 94132
~~Toll-free (800) 451-0608 (9 AM to 4 PM Pacific Time)~~
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Michael F. Cataldo, Ph.D.
Director of Psychology
The Kennedy Institute
The Johns Hopkins University
707 North Broadway
Baltimore, MD 21205
(301) 550-9455

For information on a specific syndrome, please contact:

Twin Cities Society for Children & Adults with Autism (TSAC)
253 East Fourth Street
St. Paul, MN 55101
(612) 228-9074

Cornelia de Lange Syndrome Foundation
60 Dyer Avenue
Collensville, CT 06022
(203) 693-0159, or toll free (800) 223-8355

Lesch-Nyhan Syndrome
William L. Nyhan, M.D., Ph.D.
Professor of Pediatrics
School of Medicine
University of California - San Diego
San Diego, CA 92093-0609
(619) 534-4150

National Fragile X Foundation
1441 York Street, Suite 215
Denver, CO 80206
(303) 333-6155, or toll free (800) 688-8765

International Rett Syndrome Association
8511 Rose Marie Drive
Fort Washington, MD 20744
(301) 248-7031

Tourette Syndrome Association
42 - 40 Bell Boulevard
Bayside, NY 11361
(718) 224-2999, or toll free (800) 237-0717

For general information about disabilities and caregiving:

PACER Center
4826 Chicago Avenue South
Minneapolis, MN 55417-1055
(612) 827-2966, or FAX (612) 827-3065

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What best describes your role with people who have developmental disabilities:

(A) Parent (B) Professional (C) Administrator (D) Other_____

The intended audience of parents and caregivers will find this information:

(A) Clear (B) Mostly understandable (C) Not Clear

How helpful will each section be to parents/careproviders:

(CHARACTERISTICS OF SELF-INJURY)
(A) Helpful (B) Somewhat helpful (C) Not helpful

(CAUSES OF SELF-INJURY)
(A) Helpful (B) Somewhat helpful (C) Not helpful

(TREATMENTS FOR SELF-INJURY)
(A) Helpful (B) Somewhat helpful (C) Not helpful

(FOR MORE INFORMATION ABOUT SELF-INJURY)
(A) Helpful (B) Somewhat helpful (C) Not helpful

Circle two topics you would like future brochures to address:

1. Positive/nonaversive behavior programming techniques
2. Effects & side effects of medications prescribed for behavior problems
3. Communicative functions of challenging behaviors
4. Finding support services & coping with challenging behavior
5. Recreational, educational, & job options for people with challenging behavior
6. Prevention and treatment of aggressive behaviors & other behavioral problems

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